

Testimony before the Senate Special Committee on Aging
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I am Gail Hunt, executive director of the National Alliance for Caregiving, a new nonprofit coalition of 14 national aging groups which came together to focus on family caregiving of the elderly. We conduct research, develop national programs, and work to increase public awareness of caregiving issues. Thank you for allowing me to come and provide a demographic picture of family caregiving of the elderly in the U.S.. These numbers help to put family caregiving into the larger perspective of long term care and illustrate the incredibly important role that caregivers play in keeping older people in the community longer.

The 1997 National Alliance for Caregiving/AARP national caregiver survey (funded by Glaxo Wellcome) revealed that 22.4 million households - nearly one-quarter of U.S. households - contain someone caring for an older relative or friend. Whether it includes intensive personal care such as bathing, dressing and feeding a parent or grandparent, or less intensive, everyday tasks such as grocery shopping, sorting out bills and insurance forms, and transporting them to doctors' appointments -- caregiving involves a great many Americans. On average, caregivers spend 18 hours per week caring for elderly relatives; and close to one in five provides "constant" care - that's 4.1 million caregivers providing at least 40 hours per week of unpaid care. Nearly one-third care for more than one person, perhaps a parent, grandparent and a close neighbor. And the average length of time spent caregiving for each person is 4 ½ years.

Fifteen percent of those being cared for are not blood relatives, but friends and neighbors. In the Black community especially, the survey revealed extensive caregiver connections to friends and neighbors who are treated as family. Pre-survey focus groups described to us that: "growing up as children, we were taught to check in on Mrs. Jones everyday and do the shopping for Old Mr. Smith across the way, as part of taking care of our own."

The vast majority -- 73 percent -- of family caregivers are women -- daughters, wives, sisters, daughters-in-law. In addition to caregiving for family members and friends, two-thirds of them work full or part time and 40 percent are also caring for children at home under 18.

What is the profile of the family caregiver? A 46-year-old Baby Boomer woman who is working and caring for her 77-year-old mother who lives nearby. The mother suffers from chronic illness, such as arthritis or heart disease or dementia. Often another family member, usually the caregiver's sister or brother, helps with the caregiving. Around 40 percent of our respondents said that they were the primary or only caregiver, which means that they are doing the vast majority of the work. When you combine that with the fact that half are doing hands-on personal care -- bathing, dressing, feeding -- you can begin to understand some of the burden.

What about work issues? Two-thirds of family caregivers work and half of these workers report having to make some adjustment to their work schedule to accommodate their elder caregiving. These adjustments range from coming in late, leaving early and taking time off from work (49%), to taking a leave of absence (11%), dropping back to part-time or taking a less demanding job (7%), to giving up work entirely (6.4%). A study commissioned by MetLife using data from the national caregiver survey estimates that for U.S. employers the loss in productivity from caregiving employees ranges between \$11.4 billion and \$29 billion per year.

What about the financial impact of caregiving on family members? We do not know how much long term care is paid for by caregivers versus coming from the older person's income and assets, but we do know that caregivers on average report out-of-pocket expenditures of \$171 per month for special food, home modifications, clothing, etc., for their care recipient. This amounts to \$2,000/year or the equivalent of an IRA.

What about the physical and emotional toll of caregiving? About 15% of all caregivers say they have experienced physical or mental health problems due to caregiving, but this number doubles to 31% for those doing the most intense caregiving. One in four caregivers say that the experience is emotionally stressful, and a majority of caregivers use positive words, like "rewarding," "loving," and "grateful" to describe the experience.

When asked that kinds of help, information, or support they would use, nearly 40% of caregivers said they didn't know - this points up the issue of lack of knowledge of what is available and how it could help. "Free time/time for oneself" was mentioned most often (17%) by those who could identify something they need.

Given that caregivers clearly understand some of the toll that caregiving can take, what are they doing in planning for their own long term care? A study that we have just completed for the Equitable Foundation, called "The Caregiving Boom: Baby Boomer Women Giving Care," concludes that nearly two-thirds of middle-aged women caregivers do not plan adequately for their own long term care. In this follow-up survey of 267 women ages 33 to 51 who participated in the original national survey, we found that, despite recognizing the financial implications of long term care, 62% have taken no action to prepare themselves.

This high incidence of insufficient financial planning held true regardless of their age, income, or the level of caregiving burden. It held true even though the percentage of women who said that caregiving represents "some" to "a great deal of hardship" financially rose from 27% to 49% in two years. It is well known that Americans in general have not done much long term care planning and that boomers in particular have been criticized for not engaging in saving, investing or retirement planning. However, since the women in our survey have themselves been caring for an older person, we expected that they would have begun to plan for their own futures. This does not appear to be true, although at 37% these caregiving women are taking steps to plan at a higher rate than the 25% for the general public 50 and older, as shown in the 1995 Harvard School of Public Health "Long Term Care Awareness" Study. Steps the women mentioned taking include saving more money (52%), obtaining more insurance (36%) indicating to others their preferences for care (9%) , and writing a will (7%).

How well prepared do these caregivers think they are for their own possible long term care? Very few feel they are "well" prepared. Over half report feeling "a little or not at all" prepared. Nearly all of the respondents believe that their own future long term care will be paid for by one of three means: private long term care insurance (31%), their own savings and investments (31%), or government insurance (34%). The belief that Medicare and Medicaid will pay for future long term care probably reflects the common lack of knowledge about the financial and medical conditions required to qualify for government coverage of long term care.

When asked what information they would like to help prepare for their future needs, one-third of the caregivers do not know. Topics mentioned in priority by others were financial planning information, information about how much their care and general living needs will cost, long term care insurance, and government assistance.

What the implications of these data about caregivers?

Unquestionably, family caregivers provide an enormous proportion of the long term care of older persons in this country -- as a matter of fact, 80% of the care of the elderly as provided by family and friends. In terms of time, intensity of tasks, private dollars spent out-of-pocket and impact on productivity at work, caregivers bear far more than their share of the burden of caring for older people, given the incorrect perception that older people in this country are "warehoused" by their families in nursing homes. It is amazing and heartening to see how much families do -- even as expectations of their dealing with medical technology increases and even with as little preparation as they have. Greater public awareness and recognition of the value of their role in long term care are the first steps we can take.

Secondly, caregivers need information and education. They need to know where to turn for disease - specific information on their older relatives; information about older adult resources available in the community, including financial, legal and paperwork assistance, transportation, and other services; information about caregiver support programs within the workplace. They need education -- not just from the acute care system on specific medical devices -- but hands-on everyday caregiving education -- how to transfer someone from bed to chair, how to bathe them, help with exercise, and oversee medications. They need information about how to plan for their own long term care: long term care insurance; planning for long term care as part of retirement; and housing and service options and how much they cost. Employers need incentives to provide greater access for their employees to eldercare information and services.

Thirdly, caregivers need respite. They need to have flexible time off from caregiving for a few hours, to run errands and have time for themselves, and for longer periods, to attend family functions, take vacations, continue working. Respite can be purchased from a paid caregiver or provided through a county social service program or by volunteers through a local church group, or as a regular part of adult day care, or through other means. But, however it is provided, caregivers need to have some time for themselves and the other parts of their lives in order to continue doing the job that is such an essential part of our long term care system.

As our population lives longer but with chronic illness, the role of the family caregiver becomes more and more important in keeping older people in the community. Adequate support for caregivers now means fewer proportional outlays of public dollars for institutional care now and in the future.